Social support, physical activity and stress as determinants of well-being in adults with intellectual disability

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

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2016

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Abstract

People with intellectual disability (ID) are likely to experience mental health concerns and poor physical health. However, there is a lack of understanding regarding what factors, specifically psychosocial factors, influence physical and mental health in this population. In people without disabilities, three factors have consistently been tied to mental and physical well-being, stress, social support, and physical activity. Though there is a plethora of research into how these three factors impact health in people without disabilities, research in people with ID is lacking.

The present study used a combination of established and novel self-report scales to collect data on the well-being, conceptualized as both physical and mental health, of 150 adults with ID. Measures of social support, physical activity and stress were also obtained. For a sub sample of participants (n=90), proxy report was obtained on identical factors. The primary goal of the study was to use structural equation modeling (SEM) to test a theoretical model of health informed solely by self-report. Secondary aims were to expand the research base on self-report in people with ID by examining use of several scales in this population and to compare self and proxy report.

People with ID were found to be capable of reporting on various aspects of life such as health, mental health symptoms, social support, stress, and physical activity. The majority of the scales used had acceptable psychometric properties, though some scales were found to need additional research in this population. Specifically, it was found that...
the scale used as a measure of mental health may perform differently in this population than in people without disabilities and that the measure of social support used may need an alternate scoring method. Agreement between raters on various scales ranged from poor to substantial with significant variation between and within scales. These results indicate that efforts should be made to obtain self-report whenever possible and proxy reports should be used with caution.

The theoretical model testing the impact of social support, physical activity, and stress on physical and mental health was determined to have acceptable to good fit. The model indicated that higher stress was associated with poorer mental and physical health while higher reports of friendships were also associated with poorer mental health. The model showed that important variables related to well-being can be modeled using self-report in this population and provide valuable information regarding the impact of stress on the health of people with ID.
Acknowledgments

I would like to extend my sincere gratitude to the Ohio Department of Mental Health and the County Boards of Developmental Disability for their support of this project. My adviser, Susan Havercamp, has been invaluable throughout the course of my graduate school career and this project as a sounding board and support system. I am also grateful to my committee members; Betsey Benson, Marc Tassé, and Rebecca Andridge for contributing their wealth of knowledge to the development of the project. Additionally, I am beyond grateful to have been based for the last 6 years at the Nisonger Center, which has provided a strong, compassionate, and innovative community in which to grow and learn.

On a personal level, I would like to thank my mother for exposing me from a very young age to people who are different and showing me the joy and value that these people bring to your life. She has been a role model for finding and appreciating the best qualities in people, even in difficult situations. Also, I would like to thank my father for being an example of hard work, grit, and focused determination towards a goal. You taught me to “do it right the first time” and “work smarter, not harder”. I am also grateful for the support that my network of friends and extended family has provided throughout my life. Lastly, I would like to thank my husband, I could not ask for more than the unconditional support you have given and continue to provide for me.

iv
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# Table of Contents

Abstract ........................................................................................................................................... ii

Acknowledgments ....................................................................................................................... iv

Vita ................................................................................................................................................ v

List of Tables ................................................................................................................................ ix

List of Figures ............................................................................................................................. x

Chapter 1: Introduction .............................................................................................................. 1

  Mental Health ............................................................................................................................ 1
  Physical Health .......................................................................................................................... 3
  Stress ......................................................................................................................................... 5
  Physical Activity ...................................................................................................................... 9
  Social Support .......................................................................................................................... 11
  Self vs. Proxy Report ............................................................................................................... 14
  Goals of Study ........................................................................................................................ 16

Chapter 2: Methods ................................................................................................................... 19

  Participants ............................................................................................................................... 19
Recruitment ........................................................................................................... 23
Procedures ........................................................................................................... 23
Measures .............................................................................................................. 24
Statistics .............................................................................................................. 30
Chapter 3: Results ............................................................................................... 19
Scale Performance and Reliability between Self and Proxy Report ................. 36
Model of Health and Health Determinants ....................................................... 41
Chapter 4: Discussion ......................................................................................... 51
Scale Feasibility for People with ID ................................................................. 51
Reliability ........................................................................................................... 57
Model of Health and Health Determinants ....................................................... 61
Clinical Considerations for using Self-Report ................................................ 64
Future Directions ............................................................................................... 66
Limitations .......................................................................................................... 67
Chapter 5: Conclusion ......................................................................................... 68
References ........................................................................................................... 70
Appendix A: Recruitment Flyer ........................................................................... 83
Appendix B: Demographic Forms ...................................................................... 85
Appendix C: BSI Standardized Alternate Wording ........................................... 88
Appendix D: Physical Health Measures .............................................................. 90
Appendix E: Physical Activity Measures ............................................................ 92
List of Tables

Table 1. Demographic information for full sample of people with ID............................... 21
Table 2. Demographic information on caregivers and people with ID in sub sample..... 22
Table 3. Top 5 stressors by rater.................................................................................. 35
Table 4. Means and standard deviation by rater and source of support......................... 37
Table 5. Correlation between self and caregiver rating of support................................ 37
Table 6. Top 3 activities reported by rater ...................................................................... 38
Table 7. Pearson correlation between PAS-ADD and BSI.............................................. 40
Table 8. Fit indices for social support model..................................................................... 41
Table 9. Standardized solutions and unstandardized solutions (standard errors) for SSSR subscales ........................................................................................................... 43
Table 10. Fit indices for BSI subscales.............................................................................. 44
Table 11. Standardized solutions and unstandardized solutions (standard errors) for 9-factor BSI subscales ........................................................................................................... 45
Table 12. Correlations between variables in SEM models.............................................. 48
Table 13. Fit indices for comparison health models......................................................... 49
List of Figures

Figure 1. Initial Model ........................................................................................................................................... 34

Figure 2. Secondary Model with Standardized Regression Weights .......................................................... 50
Chapter 1: Introduction

Increased public attention has been drawn to the issue of health and disability by the US Surgeon General’s Call to Action and Healthy People 2020, both public health recognitions of the health disparities that exist for people with disabilities (US Department of Health and Human Services, 2005; US Department of Health and Human Services, 2010). Among people with disabilities, one group of particular concern is people with intellectual disability (ID). ID is a disability characterized by limitations in both cognitive functioning and adaptive skills that occurs before the age of 18 (Schalock et al., 2010). Prevalence of ID is estimated to be 1% of the population worldwide (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). This sub-group of people with disabilities may have different outcomes due to social stigma, decreased community access, and a variety of other stressors and risk factors unique to this population (Cummins & Lau, 2003; Jahoda & Markova, 2004; Paterson, McKenzie & Lindsay, 2012). Recent research has highlighted that people with an ID have an increased risk for poor mental and physical health.

Mental Health

Prevalence estimates of mental health conditions in people with ID have ranged from 13.9% to 75.2%, the estimates varying widely based upon study design, population studied, and diagnostic criteria (Buckles, Luckasson, & Keefe, 2013). For example,
many of the studies that reported higher prevalence rates used mental health symptoms as a caseness criterion and/or used sample of convenience as opposed to population samples. In addition, some studies include problem behaviors and autism spectrum disorders (ASD) in their estimates of prevalence, which inflates the estimate. Cooper et al., (2007) provides one of the best estimates of prevalence though the use of a population based sample and strict diagnostic criteria. This group reported a prevalence of mental health disorders at 22.4%, this number excluded people presenting solely with behavior problems or ASD. This is slightly higher than the reported rate in the general population of the United States (Satcher, 2000). While some researchers cite the higher prevalence estimates as indicating that people with ID have a higher incidence of mental health concerns than the general population, others emphasize the inconsistencies and methodological weakness as driving the effect and believe that the incidence of mental health concerns are closer to that of people without disabilities (Buckles, Luckasson, & Keefe, 2013). Despite the lack of a definitive prevalence estimate, it is clear that mental health is a salient issue for people with ID.

Despite evidence documenting the need for mental health research and services, there is a paucity of empirical evidence on the treatment of mental health concerns in people with ID. A body of research has addressed pharmacological treatment, particularly as used to regulate behavior. People with ID are one of the heaviest medicated populations, with studies indicating that approximately 60% of people with ID are taking at least one psychotropic medication (Reiss & Aman, 1997; Tsiouris, Kim, Brown, Pettinger, & Cohen, 2013). Despite high rates of usage, adequate research on the
efficacy and side effect profiles of psychotropic medication is lacking (Ghosh, Arulrajan, & Baldwin, 2010; Matson & Mahan, 2010; Santosh & Baird, 1999). Recently, greater attention has been paid to non-pharmacological treatments for people with ID, such as psychotherapy. A review paper found a total of 25 studies that addressed the use of psychotherapy for people with ID (Brown, Duff, Karatzias, & Horsburgh, 2011). Cognitive-behavioral therapy was the most frequently studied; however, the authors cited an overall lack of evidence, specifically a lack of controlled studies using reliable and valid outcome measures. One impediment to this line of research has been the lack of understanding into what factors may impact development and maintenance of poor mental health in this population.

**Physical Health**

Advances in research methods and the inclusion of a disability identifier on surveillance tools have allowed researchers to explore the health of people with ID and compare it to people without disabilities (Krahn, Hammond, & Turner, 2006). Multiple studies have compared large representative groups of people with ID to people without disabilities and found that people with ID are more likely to report fair or poor health (Haider, Ansari, Vaughan, Matters, & Emerson, 2013; Havercamp & Scott, 2015). Similar or higher rates of chronic health condition such as arthritis, asthma, cancer, diabetes, high blood pressure, high cholesterol, cardiovascular disease, and stroke have been found when compared to people without disabilities (Reichard, Stolzle, & Fox, 2011; Patja, Eero, & Iivanainen, 2001; Shireman, Reichard, Nazir, Backes, & Greiner, 2010). Higher levels of constipation, epilepsy, hyperlipidemia, and osteoporosis have all
been reported among adults with ID (Tyler, Schramm, Karafa, Tang, & Jain, 2010). Given that people with ID appear to be a population vulnerable to poor health and health outcomes compared to people without disabilities, it is important to understand how physical health impacts other areas of life and what factors may contribute to physical health outcomes.

A strong relationship exists between physical and mental health. This is likely a bi-directional relationship with physical health influencing mental health and vice versa. Chronic health conditions may lead to isolation and decreased activity while poor mental health may lead to a decrease in self-care or a lack of follow through with health provider advice (DiMatteo, Lepper, & Croghan, 2000; Stein, Cox, Afifi, Belik, & Sareen, 2006). Higher incidence of mental disorders are correlated with a variety of medical conditions such as chronic pain, cancer, heart disease, arthritis, lung disease, high blood pressure, and diabetes (Audrey, 1988; Egede, 2007; McWilliams, Cox, & Enns, 2003; Wells, Golding, & Burnam, 1989). Both self-reported health and objective measures of health are risk factors for the development of mental health concerns (Egede, & Zheng, 2003; Koster, Bosma, Kempen, Penninx, Beekman, Deeg, & van Eijk, 2006; Prince, Patel, Saxena, Maj, Maselko, Phillips, & Rahman, 2007). In addition, people with severe mental disorders are more likely to be in poor health and to develop poor health over time (Penninx, Leveille, Ferrucci, Van Eijk, & Guralnik, 1999; Pratt, & Dey, 2007). Though mechanisms of action are still being studied, the link between mental disorders and altered immune function is thought to be at least partially due the impact of proinflammatory cytokines, which can activate in response to psychological stress, on
the working of the central nervous system (Dowlati, Herrmann, Swardfager, Liu, Sham, Reim, & Lanctôt, 2010; Jones, & Thomsen, 2013).

The link between physical and mental health in people with ID has not received research attention despite increased interest in the health of this population. Nor has research focused on understanding how other psychosocial factors may impact the health of people with ID. Understanding the factors that contribute to the development and maintenance of health problems in people with ID would inform prevention and treatment efforts and direct future policy. In people without disabilities, the environmental and personal factors that contribute to mental and physical health have been well researched. The following three factors have consistently been tied to mental and physical health: stress, social support and physical activity. Each of these factors has been shown to impact health directly or indirectly such as social support buffering the negative impact of stress (Cohen & Wills, 1985). Research into how these factors influence health in people with ID is needed as this population experiences different life circumstances and challenges when compared to people without disabilities.

**Stress**

The fact that stress has an adverse impact on both physical and mental health is well established in the research literature. A stressor is any event that is perceived by an individual as challenging and taxing to their ability to cope (Lazarus & Folkman, 1984). When faced with such a stressor, the individual will use cognitive appraisal to assess the situation and determine their ability to cope with the stressor. How the person evaluates the severity of the stressor will be based on previous life experiences, their available
support system, and their personal beliefs. The field of psychoneuroimmunology studies stress with a focus on the interaction of psychosocial factors, the central nervous system, the immune system and disease (Keller, Schleifer, Bartlett, Shiftlett, & Rameshwar, 2000). People who experience stress, both laboratory (artificially created) stress and naturalistic stress, experience immune system changes that are linked to increased vulnerability to a variety of negative health outcomes (Segerstrom, & Miller, 2004). The link between stress and cardiovascular disease has been well established, with both acute and chronic stress linked to an increase risk of cardiovascular disease (Dimsdale, 2008). Chronic stress doubled the risk of fatal strokes and increased the risk of fatal or nonfatal cardiovascular incidents in men (Öhlin, Nilsson, Nilsson, & Berglund, 2004). Stress has been linked to negative outcomes for people with multiple sclerosis, skin disease, cancer, and wounds (Kemeny & Schedlowski, 2007).

Stress is also associated with negative outcomes in mental health. Stress has been found to impact the course and recurrence of nearly every mental health disorder (Marin et al., 2011). Number of stressful life events reported has been linked to the onset and duration of depressive episodes (Kendler, Karkowski, & Prescott, 1999; Kendler, Walters, & Kessler, 1997). For patients with bipolar disorder, chronic stress was linked with an increase in symptoms (Kim, Miklowitz, Biuckians, & Mullen, 2007). Additionally, psychotherapy based on reducing stress through mindfulness training has been found to have an impact on both clinical and nonclinical mental health concerns (Brown, Brown, & Dibiasio, 2013; Grossman, Niemann, Schmidt, & Walach, 2004).
While the human body is designed to cope with stressful situations, chronic stress puts a strain on several bodily systems and has negative health outcomes. Allostasis is the process of maintaining homeostasis in the body through change and adaptation. Stress hormones such as cortisol and adrenaline are largely responsible for responding and adapting to events the body and brain perceive as stressful. Though these hormone changes are generally beneficial, as in an adrenaline surge to fuel a fight or flight response, chronic stress causes this system to remain constantly engaged, flooding the body with cortisol, adrenaline, and other hormones. Chronic stress occurs when a person experiences either ongoing difficulty following a one-time event (loss of job) or an ongoing stressful process (adjusting to a change in life circumstance). During times of chronic stress an excess production, called allostatic overload, of these types of hormones can cause changes within brain systems and structures that cause long term damage. These structural and systemic changes may explain how stress is related to mental health and chronic health problems (McEwen, 2004).

Individuals with ID, regardless of severity of intellectual impairment, respond to stress just as people without disabilities (Hatton & Emerson, 2004). Chaney (1996) showed that individuals with profound ID, unable to communicate psychological stress response, still showed a physiological stress response to changes in their environment. People with an intellectual disability report levels of stress similar to or higher than that of people with other types of disabilities (Bramston & Mioche, 2001; Bramston, Fogarty, & Cummins, 1999). This is troubling as people with ID have been found to have fewer resources available to help cope with stress, and a history of negative coping experiences.
Given these differences it is important to study the impact of stress on health in people with ID.

While there is a lack of research examining the impact of stress on physical health in people with ID, there has been some research that links stress with adverse mental health outcomes. Hartley and MacLean compared 47 depressed adults with mild ID to a matched sample if adults without disability and found that adults with ID experienced more stress and had frequent stressful social interactions (2009). Individuals with ID who have experienced a recent loss rated higher on scales of mental health symptoms and problems. Similarly, current mental health symptoms were associated with higher levels of stressful life events (Hubert-Williams & Hastings, 2008). Martorell et al. looked at the presence or absence of an ICD-10 mental health diagnosis in relation to both traumatic life experiences and stressful life events in a sample of 177 adults with mild or moderate ID (2009). Traumatic life experiences were events such as physical or sexual assault, natural disaster, or a life threatening illness. Stressful life events consisted of events such as bereavement, the end of a relationship, loss of a job, or moving residences. Both traumatic and stressful life events were significant predictors of an ICD-10 mental health diagnosis. A similar study with a larger sample size (n >1,000), found that the presence of one or more stressful life events in the previous 12 months increased the odds ratio for affective disorders in a population of adults with ID (Hastings, Haton, Taylor, & Maddison, 2004). A similar study found that this relationship held, even after controlling for age, problem behavior, and other disabilities (Owen et al., 2004). In a study of 151 adults with mild to moderate ID, the number of
life events experienced in the previous six months was a predictor of current depression (McGillivray & McCabe, 2007). Stressful life events were correlated with both the presence of a mental health disorder and behavior problems in a large nationally representative sample of adults with ID (Scott & Havercamp, 2014). In conclusion, research has consistently shown that stress and stressful life events have a negative effect upon the mental health of people with ID.

Given the strong association between stress and negative health outcomes and the research showing that people with ID may experience increased levels of stress and have fewer coping skills, it is important to consider what factors may play a protective role in health outcomes. In people without disabilities both regular physical activity and social support have consistently been shown to have a positive impact on physical and mental health.

*Physical Activity*

The physical and mental health benefits of exercise are well-documented and have received considerable attention as a public health intervention (Bertheussen, Romundstad, Landmark, Kaasa, Dale, & Helbostad, 2011). A lack of physical activity contributes to obesity and a large number of adverse medical conditions such as diabetes, coronary heart disease, stroke, and premature death (Warburton, Nicol, & Berdin, 2006). Starting or increasing a physical activity regimen is associated with gains in health and quality of life (Bauman, 2004; Powell, Paluch, & Blair, 2011; Pucci, Reis, Rech, & Hallal, 2012). In addition to physical activity impacting physical health, it also has been linked to better mental health. Several large meta-analyses have shown that
physical activity may have a positive effect on both depression and anxiety (Chu, Koh, 

Physical activity also serves as a buffer between life stress and negative physical 
and mental outcomes. In the elderly, physical activity slowed the rate of functional 
decline and buffered the effect of widowhood on functional decline (Unger, Johnson & 
Marks, 1997). In studies of adolescents and adults the psychological and physical effects 
of stress were decreased by high levels of physical activity (Brown & Siegel, 1998; 
Carmack, Boudreaux, Amaral-Melendez, Brantley, & de Moor, 1999; Norris, Carroll & 

Several mechanisms have been proposed to explain the positive impact of 
physical activity on mental health. Psychosocial mechanisms include: distraction ,where 
engaging in physical activity takes one’s mind off negative events, self-efficacy, where 
physical activity increases feeling of competence, and social interaction, physical activity 
often involves other people and group events (Peluso & Andrade, 2005). Physiological 
mechanisms that may explain the positive impact of physical activity on mental health 
include the release of monoamines and endorphins. Physical activity, like some 
antidepressants, stimulates the transmission of monoamines (Ransford, 1981). Most 
research, however, attributes the apparent psychological benefits of exercise to the 
release of endorphins. Endorphins are produced by the pituitary gland and the 
hypothalamus during exercise and are responsible for producing a sense of well-being 
and analgesia (Dinas, Koutedakis, & Flouris, 2011). The mechanisms by which physical 
activity impact mental health are not yet known and warrants further study.
The same physical health benefits from regular physical activity and increased health risks from a lack of physical activity were found in samples of adults with ID (Johnson, 2009). A handful of studies examined the psychological benefit of physical activity in this population. Participation in an exercise program increased feeling of social well-being and increased positive feelings regarding physical appearance in adults with ID (Carmeli, Vaknin, Morad, & Merrick, 2005). Participation in an exercise program led to higher life satisfaction and lower rates of depression in adults with Down syndrome (Heller, Hsieh, & Rimmer, 2004). Unfortunately, despite the benefits of physical activity on mental and physical health, research has consistently shown that individuals with ID have a lower level of physical fitness and lower levels of physical activity when compared to people without disabilities (Rimmer, Heller, Wang, & Valerio, 2004; Frey, 2004; Havercamp, Scandlin, & Roth, 2004).

Social Support

Research linking social support to positive physical and mental health outcomes is abundant. In terms of physical health, people with strong support networks have been showed to have decreased risk of mortality from disease and better self-reported health outcomes (Lyyra, & Heikkinen, 2006; Tomaka, Thompson, & Palacios, 2006). A strong social support network has been associated with recovery outcomes for people with cancer, cardiovascular disease, diabetes, hypertension, liver disease, and arthritis (Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Tomaka, Thompson, & Palacios, 2006; Uchino, 2006). In terms of mental health outcomes, social support has been linked with decreased risk of developing psychopathology, faster recovery times,
and some evidence suggests that targeting social support may be an avenue for mental health intervention (George, Blazer, Hughes, & Fowler, 1989; Kawachi, & Berkman, 2001; Kessler, Price, & Wortman, 1985).

Many psychological mechanisms have been proposed towards understanding how social support may impact health. Seven of these mechanisms have been discussed in the literature: social influence, social control, role obligations, self-esteem, sense of control, belonging and companionship, and perceived support. Social influence refers to how information and norms regarding health and health behaviors may be transferred between people in a social circle (Marsden & Friedkin, 1994). Social control posits a more direct impact, consisting of members of the social network exerting their influence to encourage or pressure a person to engage in positive health habits or to stop destructive ones (Umberson & Montez, 2010). Role obligations refer to the fact that social ties generally are constrained to specific roles such as friend or sister. These roles provide both guidance for behavioral action and a sense of purpose or meaning that may positively impact health (Rosenberg & McCullough, 1981; Thoits, 2003; Umberson & Montez, 2010). The fulfillment of role obligations may increase one’s sense of self-esteem or self-worth and give a person a feeling of mastery over their life (Rosenberg, Schooler, Schoenbach, & Rosenberg, 1995; Taylor & Stanton, 2007; Thoits, 2011). Social ties can also serve to provide a person with a sense of belonging and companionship. This gives the person a sense of interconnectedness that may increase positive affect and influence health (Rook & Underwood, 2000; Uchino, 2004). Lastly, simply the perceptions that people are available to provide emotional, informational, and
instrumental support in times of need may be reassuring enough to impact health (Cohen & Wills, 1985; Uchino, 2004). While these processes are largely indirect and passive it is hypothesized that when a stressor occurs a different process may come into play.

Social support not only has a direct impact on well-being, it also buffers the negative impact of stress on physical and mental health. Thoits (2011) argues that while social ties impact health in the seven ways discussed previously in a largely passive and invisible manner, this changes when a person is experiencing stress and the support assumes a more active role. In times of stress, the relevant members of a person’s social circle mobilize to provide visible and deliberate support in several key ways. This includes providing emotional, instrumental, and informational assistance directed towards changing the stressful situation, providing emotional sustenance such as sympathy and caring and providing a positive example and relevant advice.

Social support has been shown to be an important component of wellbeing; however, research suggests that adults with ID may not have access to social support to the same degree as adults without disabilities and with other types of disabilities. People with ID report smaller social circles than people with physical disabilities, and the content also differs in that adults with ID report more paid staff support and less support from friends and family (Lippold & Burns, 2009). A similar study found that people with ID receive a significant amount of their support from paid staff members (Amado, 1993). The staff members can certainly provide support for people with ID; however, these types of relationships are likely to be transient and not reciprocal. A study which compared large nationally representative samples of people with ID, other disabilities, and no
disabilities found that people with ID were more likely to report inadequate support than either of the two other groups (Havercamp, Scandlin, & Roth, 2004, Havercamp & Scott, 2015).

A small number of studies have contributed to understanding the role of social support in people with ID. A retrospective study in a large representative sample of adults with ID living in the US found that a lack of social support was correlated with a two-fold increase in likelihood of having been diagnosed with a mental illness (Scott & Havercamp, 2014). Social support is positively correlated with quality of life and negatively correlated with depression in adults with ID (Lunsky & Benson, 2001; Meins, 1993). However, more research is needed to fully understand how social support may interact with other variables in a person’s life to impact well-being.

Self-report vs proxy reports

Research practices regarding how to obtain information about the lives of people with ID has undergone a shift in recent years. While previous research relied mostly on proxy report, there has been an increased effort to obtain information directly from the person with ID whenever possible. There are many considerations to take into account when gathering self-report data from people with ID. The cognitive demands inherent in self-reporting are complicated and may present stumbling blocks for people with ID at each step in the process. A model commonly referenced breaks down response to survey items into 4-steps (1) accurate interpretation of the question, (2) retrieval of information, (3) judgement of retrieved information, and (4) formatting a response (Tourangeau, Rips, & Rasinski, 2000). This cognitive process taps into comprehension, memory, ability to
compare across time and people, and verbalize correct responses. As people with ID, by
definition, have impairments in cognition, these processes are likely all impacted
(Fujiura, 2012). To address these impairments, recommendations have been made to
increase the accuracy of self-report. These include using minimalistic wording, checking
for comprehension by asking for examples, using concrete examples, and asking for
specifics rather than generalities (Finlay & Lyons, 2001).

While proxy report may be easier to obtain, it is limited by the fact that a proxy
can never know the internal physical and mental state of another person. This is
particularly relevant for subjective topics such as mental health, quality of life,
relationships, and stressors. Obtaining self-report is likely more valid, promotes inclusive
practices and places a greater emphasis on self-determination. While there has been an
increase in the use of self-report for research purposes, many of the studies that use self-
report to examine health in people with ID have limited the sample to those with
borderline and mild cognitive impairments (Fujiura, 2012; Kellett, Beail, Newman, &
Frankish, 2003). In contrast to these restrictions, a recent study used data gathered by the
National Core Indicators, a large scale representative survey of adults with ID, to look at
the ability to self-report on a variety of topics. Of the over 11,000 participants ranging
from borderline to profound cognitive impairments, researchers found that 62.1% of
people were able to respond to self-report questions on employment, home situation,
safety, health, relationships, and transportation, further that interviewers felt that the
questions were well understood by participants (Stancliffe, Tichá, Larson, Hewitt, &
Nord, 2015). Though the use of self-report is encouraged by researchers and advocates
in the ID field, there is lack of methodological guidelines for how best to obtain this information and a lack of self-report scales with strong psychometric properties. For the emerging scales that have been designed, there is also a lack of independent evaluation and rigorous testing.

A commitment to gathering self-reported information in this population is an ethical responsibility because proxy report does not always agree with self-report. For example, there are several studies that have shown proxy and self-report to vary greatly when assessing subjective subjects such as quality of life, social support and stress. Several studies on quality of life have shown that people with ID report greater satisfaction than proxy reporters and differ on several key areas (Balboni, Coscarelli, Giunti, & Schalock, 2013; Schmidt, Power, Green, Lucas-Carrasco, Eser, Dragomirecka, & Fleck, 2010). Comparisons of staff and self-report of social support have shown that while there is better correlation between raters on family and staff support systems, there is poor agreement when it comes to friends and romantic partner support (Lunsky, & Benson, 1997). Reporting of stress also varies between raters and adults with ID, specifically proxy reporters may focus on perceived inadequacies (such as having a disability) as being particularly stressful, though this is not reported by the person themselves (Lunsky, & Bramston, 2006). Given the highly subjective nature of factors such as social support and stress, it is essential to use self-report measures. This is also particularly true for collecting information on mental health symptomology. The diagnostic criteria for many mental health conditions contain symptoms that a proxy reporter simply cannot know, such as feeling guilty, or having constant worry. Though a
proxy reporter may make every effort to understand and relate to the person with ID, they will never be able to report as accurately on internal states as the person themselves.

**Goals of study**

Primary Goal- The primary goal of this study is to use data based entirely upon self-report to test a theoretical model of health determinants in adults with ID. Structural equation modeling (SEM) is used to test a theoretical model representing the relationship of several well-known determinants of health. While several of these factors have been explored previously in people with ID, to our knowledge this is the first study to rely entirely upon self-report and to integrate these finding into a theoretical model. This model will provide a framework for understanding how and to what extent different factors impact well-being in adults with ID according to adults with ID. It is important to model these relationships in adults with ID since they experience different stressors, different types of social support, and less physical activity than people without disabilities. Results from these analyses can inform practice and policy, especially in terms of service planning for people with ID.

Secondary goals- Secondary aims of this study are twofold. First this study used scales to measure aspects of life that have received little to no research attention in people with ID. Discussion of these scales, their proprieties and utility will provide guidance to future researchers interested in this area. In addition, while much of the previous research using self-report in this population has used a restricted sample based on level of cognitive functioning, this study did not exclude participants based upon a documented
level of functioning. Therefore results from this study will provide valuable information on scale performance with a broad range of adults with ID.

Finally, a caregiver will also provide a proxy report for each construct of interest (physical health, mental health, stress, social support). Though there has been previous research using proxy and self-reported measures of mental health in people with ID, there is no research comparing these respondents (Keller at al., 2003, 2004; Prosser, Moss, Costello, Simpson, & Patel, 1998). This study will replicate and expand upon previous research on comparison of proxy and self-report that have been conducted in the areas of stress and social support (Lunsky & Benson, 1997; Lunsky & Bramston, 2006). A comparison between proxy and self-report of physical activity and physical health has never been reported in the literature. Though caregivers are often used as proxy reporters for people with ID, there is a lack of research examining the validity of those reports. This study will add to the literature and provide information on how proxy and self-report compare in several important areas of life. While the emphasis will be placed upon the information gathered from the individuals themselves, proxy report is included for several reasons. Though this study will include only adults with the ability to verbally report, there are many people with ID who are not able to communicate their internal states using a rating scale. For these people, caregivers will serve as proxy reporters in many situations and it is important to understand how accurate these reports may be. By comparing proxy and self-report in this population, information can be provided that may provide context in situations where only proxy report is available.
Chapter 2: Methods

Participants

Participants with ID were 150 adults receiving services in one of three Ohio counties who were interested in participating in a study about health and well-being. Inclusion criteria included being over the age of 18, and able to respond to questions either verbally, with sign language, or through writing. People with and without guardians were included in the study. The study sample was 64.7% male and the average age was 37 years (SD=12.6, range 18 to 70). After the completion of the study, information on degree of cognitive impairment was obtained for approximately 60% of the sample (N=89) from their County Board of Developmental Disability. Of this group 55% had a diagnosis of mild ID, 35% moderate ID, and 10% were unspecified. See Table 1 for full demographic information on the participants. This information is based off the self-report demographic form.

A subsample of the participants had a caregiver that participated in the study (n=90, 60% of study sample). This included paid staff, family members, and significant others. Caregivers consisted of 9.1% parents, 3.4% other family members, 75.1% paid staff, and 12.5% other which included guardians and significant others. Caregivers other than family members had known participants an average of 2.67 years (range 3 months - 14 years). See Table 2 for full demographic characteristics of caregivers and people with ID in this sub sample. Differences in demographic variables between the group of people
with ID without caregiver participation and the subgroup that had caregiver participation were examined using a chi squared statistic. The group with caregiver participation was significantly less likely to be employed $\chi^2(1, N=56)=23.2, p<.05$, to be living with family $\chi^2(1, N=56)=26.65, p<.05$, and to have no staff $\chi^2(1, N=56)=16.54, p<.05$. No other significant differences between groups were present.
<table>
<thead>
<tr>
<th>Table 1. Demographic information of full sample of people with ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=150</td>
</tr>
<tr>
<td>Male                                                         64.7% (97)</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>18-34                                                        48.6% (72)</td>
</tr>
<tr>
<td>35-54                                                        39.9% (59)</td>
</tr>
<tr>
<td>≥55                                                          11.5% (17)</td>
</tr>
<tr>
<td>Race</td>
</tr>
<tr>
<td>White                                                        78.7% (118)</td>
</tr>
<tr>
<td>Black                                                        20% (30)</td>
</tr>
<tr>
<td>Other                                                        1.4% (2)</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>Hispanic                                                     2% (3)</td>
</tr>
<tr>
<td>Non-Hispanic                                                 98% (146)</td>
</tr>
<tr>
<td>Job status</td>
</tr>
<tr>
<td>Full time                                                    10.6% (16)</td>
</tr>
<tr>
<td>Part time                                                    63.8% (95)</td>
</tr>
<tr>
<td>Unemployed                                                   25.5% (38)</td>
</tr>
<tr>
<td>Living Situation</td>
</tr>
<tr>
<td>Living alone                                                 26.7% (40)</td>
</tr>
<tr>
<td>Living with roommates                                       47.3% (71)</td>
</tr>
<tr>
<td>ICF-IDD                                                      5.3% (8)</td>
</tr>
<tr>
<td>Living with family                                          18% (27)</td>
</tr>
<tr>
<td>Living with significant other                                2% (3)</td>
</tr>
<tr>
<td>Staffing Situation</td>
</tr>
<tr>
<td>24-hour staffing                                            70.1% (101)</td>
</tr>
<tr>
<td>Less than 24-hour staffing                                   23.6% (34)</td>
</tr>
<tr>
<td>Living independently or with natural supports only           6.3% (9)</td>
</tr>
</tbody>
</table>
### Table 2. Demographic information on caregivers and people with ID in sub sample

<table>
<thead>
<tr>
<th></th>
<th>ID (N=90)</th>
<th>Caregivers (N=90)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td>64.4% (58)</td>
<td>35.6% (32)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-34</td>
<td>53.3% (48)</td>
<td>37.2% (32)</td>
</tr>
<tr>
<td>35-54</td>
<td>35.6% (34)</td>
<td>43% (37)</td>
</tr>
<tr>
<td>≥55</td>
<td>11.1% (10)</td>
<td>19.8% (17)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>78.9% (71)</td>
<td>31.3% (26)</td>
</tr>
<tr>
<td>Black</td>
<td>18.9% (17)</td>
<td>61.4% (51)</td>
</tr>
<tr>
<td>Other</td>
<td>2.2% (2)</td>
<td>7.2% (6)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.1% (1)</td>
<td>3.1% (2)</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>98.9% (89)</td>
<td>96.9% (63)</td>
</tr>
<tr>
<td><strong>Job status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>13.5% (12)</td>
<td>75.3% (67)</td>
</tr>
<tr>
<td>Part time</td>
<td>46.1% (41)</td>
<td>16.9% (16)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>40.4% (36)</td>
<td>7.9% (7)</td>
</tr>
<tr>
<td><strong>Living Situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>32.2% (29)</td>
<td></td>
</tr>
<tr>
<td>Living with roommates</td>
<td>39.8% (34)</td>
<td></td>
</tr>
<tr>
<td>ICF-IDD</td>
<td>4.4% (4)</td>
<td></td>
</tr>
<tr>
<td>Living with family</td>
<td>11.1% (10)</td>
<td></td>
</tr>
<tr>
<td>Living with significant other</td>
<td>3.3% (3)</td>
<td></td>
</tr>
<tr>
<td><strong>Staffing Situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24-hour staffing</td>
<td>68.5% (61)</td>
<td></td>
</tr>
<tr>
<td>Less than 24-hour staffing</td>
<td>28.1% (25)</td>
<td></td>
</tr>
<tr>
<td>Living independently or with natural supports only</td>
<td>3.4% (3)</td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to person with ID</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>9.1% (8)</td>
<td></td>
</tr>
<tr>
<td>Other relative</td>
<td>3.4% (3)</td>
<td></td>
</tr>
<tr>
<td>Paid staff</td>
<td>75.1% (66)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>12.5% (11)</td>
<td></td>
</tr>
<tr>
<td><strong>Highest level of education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>40.9% (36)</td>
<td></td>
</tr>
<tr>
<td>Associate Degree</td>
<td>26.1% (23)</td>
<td></td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>19.3% (17)</td>
<td></td>
</tr>
<tr>
<td>Advanced Degree</td>
<td>5.7% (5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8% (7)</td>
<td></td>
</tr>
</tbody>
</table>
Recruitment

Participants with ID were recruited through the Franklin, Delaware, and Licking County Boards of Developmental Disabilities, Nisonger Behavior Support Services, and various residential and day program agencies in Franklin, Delaware, and Licking Counties. The county boards are county agencies providing supports such as service coordination, residential supports, therapy, community employment, and recreation opportunities to adults and children with developmental disabilities. Service Coordinators, Behavior Support Specialists, and Supervisors of day programs and residential providers presented flyers describing the study to clients on their caseload that met inclusion criteria (see Appendix A). If clients expressed interest in participating in the study, their contact information was passed on to the researchers.

Procedures

All the following procedures were performed by one of two researchers who were doctoral students in a psychology program that provides training specific to working with people that have intellectual and developmental disabilities. Participants with ID who expressed interest in the study were contacted by a researcher via telephone or in person if the study information was presented at a day program that the person attended. If the individual had a guardian, the guardian was first contacted by the researchers who thoroughly explained the study and obtained written consent. Appointments were set up with the individual at a location of his or her choosing, usually at their home or work/day program. Before the appointment, the person was asked if they had a caregiver who
would be willing to participate with them. During the face to face meeting, the
researcher explained the study and obtained consent or assent of both the individual and
if applicable, their caregiver. After consent was obtained, the following questionnaires
were completed in a structured interview format with the individual with ID: (1)
Demographic form, (2) Social Support Self Report (SSSR), (3) Physical Activity
Questionnaire, (4) Brief Symptom Inventory (BSI), (5) Physical Health Questionnaire,
(6) Lifestress Inventory. After providing consent, the following questionnaires were
completed by the caregiver of the person with ID: (1) Caregiver Demographic form, (2)
Social Circles Questionnaire (SCQ), (3) Physical Activity Questionnaire, (4) PAS-ADD
Checklist, (5) Physical Health Questionnaire, (6) Lifestress Inventory-Informant version.

All questionnaires were reviewed with caregivers prior to administration. The
caregivers were asked to complete the questionnaires on site in a separate room during
the interview, or to take the questionnaire packet home and return it to the researchers at
a later date. The packet included an instruction sheet for each questionnaire and contact
information to reach the researchers with any questions.

Measures

Demographic forms

Three demographic forms (see Appendix B) were used to collect information
from participants. The participant with ID completed a basic demographic form about
themselves as part of the interview process. The caregiver participants completed two
demographic questionnaires, one about themselves and one about the person for whom
they were providing care.
Mental health

The PAS-ADD checklist was used to obtain a proxy report of mental health. The PAS-ADD checklist is a 25-item screening tool designed for use by nonprofessionals to screen for mental health disorders and evaluate need for additional services in people with ID (Prosser, Moss, Costello, Simpson, & Patel, 1998). The majority of the checklist consists of items from the full length, interview format PAS-ADD (Moss, Goldberg, Patel, Prosser, Ibbotson, Simpson, & Rowe, 1995) and cut-off scores are provided to assist with interpretation. In the initial studies of the checklist, the authors reported good validity, though inter-rater reliability was fairly low (Prosser, Moss, Costello, Simpson, Patel, & Rowe, 1998). The checklist was later normed using a large sample that consisted of both community patients and hospital patients with ID (Taylor, Hatton, Dixon, & Douglas, 2004). Other studies have reported similar psychometric properties as the initial study (Hatton & Taylor, 2008; Sturmey, Newton, Cowley, Bouras, & Holt, 2005). There have been a few studies that have used factor analysis to try and discern an underlying structure. However, these results have been inconsistent between and even within studies (Hatton & Taylor, 2008; Moss et al., 1998). For this reason, the threshold scores and symptom groupings provided in the PAS-ADD checklist manual were used in all analyses.

The Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) was used to obtain self-report of mental health symptoms. The BSI is a brief screening instrument based on the Symptom Checklist-90-R, an extensively tested self-report inventory (Derogatis, 1996). The BSI has been tested extensively in people without disabilities and
has been found to have adequate internal consistency and construct validity (Boulet, & Boss, 1991).

The BSI has been used in people with ID. Keller et al. (2003, 2004) evaluated the BSI in a sample of 200 people with mild ID that fell into one of three groups; clinical, community, or forensic. In a second study, Keller reported an 8 factor structure derived from exploratory factor analysis. The second sample consisted of 335 people with mild ID with no reference to existing psychopathology and the authors reported that participants with ID were able to respond to the questions on the BSI and that responses effectively differentiated between group membership in the first study. The tool demonstrated similar internal consistency to what was demonstrated in people without disabilities. A recent study used a Dutch translation and interview format of the BSI to evaluate 224 adults with ID who had an established mental health disorder (Wieland, Wardenaar, Fontein & Zitman, 2012). They reported that the BSI was a useful tool in this population, that the questions were easily understood by the participants with only an average of four questions needing further explanation from the interviewer. Internal consistency, construct and discriminate validity, and factor structure were all reported to be similar to the psychometrics established in people without disabilities. The authors concluded by supporting the use of the BSI as a self-report screener for psychopathology in people with ID. For the present study, the BSI was used in an interview style format. Pictures of faces displaying various emotions were also used to help participants distinguish between responses on the 5 point scale. Early in the study process researchers noted that additional explanation was needed for many of the BSI items. A standardized
alternate wording form was created by the researchers and used when participants required clarification or additional explanation (see Appendix C).

Physical health

The physical health of people with ID was explored using a three question measure designed by the researchers (see Appendix D). The measure was identical for the self and proxy report with just the wording changed to reflect the point of view. One question asked for a subjective report on the overall health of the participant, this is supported by previous research that has asked both staff and the individual to rate health via this method (Fujiura, 2012). The second question asked about how often the individual missed activities or events due to health concerns, while the last question asked about fatigue. The questions and responses are worded simply, taking into consideration the suggestions by Finlay and Lyons (2001). A composite score ranging from 3 (person endorsed the best health in all options) to 9 (person endorsed worse health in all options) was created by summing the three items.

Stress

The Lifestress Inventory is a 30 item checklist of stressful life events developed specifically for adults with ID (Bramston, Bostock, & Tehan, 1993). This checklist was developed through focus groups of people with and ID and staff members and was designed to be easily understood and completed by people with mild ID. The initial studies of the instrument found it to be internally reliable with a Chronbach’s alpha of .80, and validity was confirmed through comparison with other established scales of stress (Bramston & Bostock, 1994). The scale was found to have a three factor structure.
consisting of general anxiety, negative interpersonal interactions, and lack of skills and coping behavior (Bramston and Fogarty, 1995). One study found that that people with ID endorsed an average of 8 stressful events on the scale and that people with ID differed in the items endorsed with the participants with ID endorsing more negative interpersonal stress than college students (Bramston, Fogarty, & Cummins, 1999).

A previous study used an informant version of this scale to assess staff’s perspective on stress experienced by people with ID (Lunksy & Bramston, 2006). For the informant report, the Lifestress Inventory was slightly reworded to take the perspective of the rater. This version used a 3-point Likert scale (0=”No, not at all”, 1=”Sometimes or somewhat”, and 2=Yes, most definitely”) as the response. This version was found to have adequate internal reliability with a Chronbach’s alpha of .77 and validity was confirmed through significant correlations with scales of negative social interactions and depression.

The original Lifestress Inventory was a Y/N checklist and the informant version gave three responses. For this study, in order to directly compare the two versions of the scale, informant responses of “sometimes or somewhat” or of “yes” were counted as “yes”. A sum score capturing the number of stressful events endorsed was used in all analyses.

Social support

The Lunsky and Benson (1997) version of the Social Support Self Report (SSSR) was used to gather self-perspective on social support. The SSSR was adapted from the Reiss-Peterson Social Support Self-Report for Mentally Retarded Adults to include staff
members (Reiss & Benson, 1985). The scale has two parts, first the person with ID is asked to name each supportive person in their life in four categories, family, friends, staff and romantic partner. Then he/she is asked five questions on the quality of that support on a 3-point Likert scale. Research using the SSSR has found the scale to have fair to excellent internal consistency, with the family scale and friends scale having better reliability than the staff and romantic partner scale. In addition, results from the SSSR were significantly correlated with other social support self-report scales and staff report of social support (Lunsky & Benson, 1997). A second study by the same authors using the SSSR found that levels of social support as reported on the measure were positively correlated with quality of life (Lunsky & Benson, 2001).

To obtain a proxy report of social support, caregivers completed the Social Circles Questionnaire (SCQ). The SCQ is a 64 item scale designed to collect information on staff perception of individuals with ID’s social support (Lunsky & Benson, 1999). It measures both network size and the quality of support given by friends, family, staff, and romantic partners. In the initial study of the instrument, authors reported good internal consistency and test-retest reliability, and moderate interrater reliability. The authors noted that interrater reliability may be impacted by the context in which each rater interacts with the individual and also that in terms of romantic relationships and friendship many raters were uncertain of support received in these areas, emphasizing the need to include self-report. In a second study the same authors reported that the SCQ was correlated with both other staff social support measures and self-report measures of
social support (Lunsky & Benson, 1997). The SCQ includes two items in each subscale designed to measure negative social interactions. These were not included in analyses.

*Physical activity*

Physical activity was assessed through a checklist of common activities in which an individual might participate (see Appendix E). Participants were asked whether or not they engage in the activity regularly (this was described as at least once per week) and, if so, they were asked to rate level of exertion during the activity. Level of exertion was assessed by asking “When you do this activity do you get tired/sweaty/out of breath?” Participants could respond “No”, “A little”, or “A lot”. Pictures were provided to the person with ID to aid them in their decision making. Staff completed the same measure, with wording changes to reflect their point of view. Similar methods of assessing physical activity have been used with success by other researchers (Peterson, Lowe, Andrew Peterson, Nothwehr, Janz, & Lobas, 2008). The method produced a total number of activities score and a sum score that took into account both total number of activities and level of exertion during those activities. The World Health Organization recommends a minimum of 150 minutes of moderate intensity or 75 minutes of vigorous intensity physical activity per week (World Health Organization, 2010). For this measure adequate physical activity was considered engaging in either two activities at moderate intensity or one activity at high intensity.

*Statistics*

All statistical analyses were conducted using SPSS version 22 and for confirmatory factor analyses and structural equation models, AMOS version 23.
**Missing data**

Though every effort was made to work through any difficulties comprehending questions, some questions were not answered by all participants due to either comprehension concerns or, in rare cases, a lack of willingness to discuss a particular topic. The issue of missing data was most relevant for the BSI. If a participant had missing data on the BSI for greater than 10% of the scale (6 or more questions) their data was discarded. Using this criterion, 2% of the sample (3 participants) was eliminated. An additional 15% of the sample (23 participants) was missing fewer than 6 questions. Missing data was replaced by the mean of that subscale. For the Lifestress Inventory, missing data was left unchanged as the scale was used as a total score. The majority of unanswered items were due to the item not being applicable to the participant. For example, “Have you been getting along well with your significant other” when the participant did not endorse having a significant other, thus it was reasonable for these skipped questions to not contribute to the total score. There were no cases of missing data for either the SSSR or the Physical Activity Questionnaire. In the case of missing data on the Physical Health Questionnaire, a missing value on one of three questions was replaced by the mean of the other two items. This guideline was applied to less than 1% of cases (1 participant).

**Scale use in this sample:**

Internal consistency was calculated for scales and subscales, when appropriate, using Cronbach’s alpha. Though recommendations vary, generally alpha’s > .70 are considered fair, scores > .80 good and >.90 excellent (Cicchetti, 1994).
Reliability between self and proxy report:

To examine self and proxy agreement between the Physical Health Questionnaire, Physical Activity Questionnaire, and Lifestress Inventory, intraclass correlation coefficients (ICC) estimated with a one-way random effects model were used. Self and proxy agreement was compared for social support and mental health using Pearson correlations. Agreement between raters was interpreted based on the following guidelines: <0.2, poor; 0.2-0.4, fair; 0.4-0.6, moderate; 0.6-0.8, substantial; >0.8 excellent (Landis & Koch, 1977; Nunnally & Ira, 1978). If any scales had nonsignificant reliability results, then additional analyses looking at type of caregiver were examined.

Structural Equation Model of health

Prior to all modeling, data was tested for assumptions of normality. Skewedness and kurtosis were both assessed and values of greater ± 2 for skewedness and greater than ± 7 for kurtosis were considered problematic (Curran, West, & Finch, 1996). For the BSI individual items, one question (Having urges to beat injure or harm someone) was over the threshold for both skewedness and kurtosis. For the CFA of the SSSR one question (How often do you see or talk to staff) was skewed. Given that for both scales there was only one variable of concern, no corrections for this were made. In the main model of health no concerns regarding normality were noted for BSI subscales, social support subscales, physical health, stress, and physical activity variables.

Factor analysis and structural equation models were estimated using maximum likelihood (ML) assuming multivariate normality. All models were evaluated using several fit indices including: the chi-square statistic ($\chi^2$), the normed chi-squared, the
comparative fit index (CFI), and the root mean square of approximation (RMSEA). These fit indices give an overall picture of how well the data fits the hypothesized model. Since the chi-squared statistic can be impacted by sample size, greater emphasis should be placed on the normed chi-squared, CFI and RMSEA fit indices (Browne and Cudeck, 1989). The CFI has values ranging from 0 to 1 with values over 0.9 indicating a good fit (Hu & Bentler, 1999). For RMSEA, values less than or equal to .05 indicate a close fit, values between .05 and .08 indicate an acceptable fit, and values above .08 indicate a poor fit (Kline, 1998). Specific pathways between latent variables are represented by squared multiple correlations ($R^2$) and regression estimates ($\beta$) measure the contribution of the observed variables that comprise each latent variable.

Pearson correlations were computed between the social support subscales, physical activity, stress, mental health subscales, and physical health. Structural equation modeling was used to assess how these three determinates of health (social support, stress, physical activity) predicted mental and physical health outcomes. In structural equation modeling, observed (measured) variables are represented by squares while latent (abstract constructs based upon observed variables) are represented by ellipses. The initial model (Figure 1) had two observed variables, stress and physical activity, and four latent variables, the social support subscales which were based on the individual social support item questions, loading onto the observed variable of physical health and the latent variable of mental health which was based on the 9 sub scales of the measure.
Figure 1. Initial Model
Chapter 3: Results

Scale performance and reliability between self and proxy report

Physical Health

Internal consistency for the self-report physical health scale was poor (3 items, $\alpha=0.60$) and the caregiver report physical health scale was also poor (3 items, $\alpha=0.61$). 67.8% of participants with ID rated their health as very good, while only 42.2% of caregivers gave the very good health rating. Overall, self and caregiver report were significantly related (ICC=.46, p<.001).

Stress

The Lifestress Inventory had poor internal consistency (30 items, $\alpha=.62$) and the Lifestress Inventory Caregiver version also had poor internal consistency (30 items, $\alpha=.65$). Participants with ID endorsed an average of 9.7 (SD=3.99, range 3-23) stressful events while caregivers endorsed an average of 8.2 (SD=3.32, range 2-17) events. The self and caregiver report on the Lifestress inventory were not significantly correlated (ICC=.077, p=.23). When caregivers were divided into family members and paid staff, the family member proxy report did significantly correlate with self-report on the Lifestress Inventory (ICC=.49, p=.046) but staff report did not (ICC=.10, p=.21). See Table 3 for the top stressors reported by self and caregiver report.
### Table 3. Top 5 stressors by rater

<table>
<thead>
<tr>
<th>Self-report</th>
<th>Caregiver report</th>
</tr>
</thead>
<tbody>
<tr>
<td>75.3% Death or illness of person they care about</td>
<td>77.8% Feels too slow/ unable to do things correctly</td>
</tr>
<tr>
<td>71.1% Underestimated by people</td>
<td>75.3% Death or illness of person they care about</td>
</tr>
<tr>
<td>68.9% Hears people arguing</td>
<td>70.8% Underestimated by people</td>
</tr>
<tr>
<td>62.9% Feels too slow/ unable to do things correctly</td>
<td>70.1% Crowded place</td>
</tr>
<tr>
<td>58.4% difficult situation didn’t know what to do</td>
<td>69.7% Been in arguments/fights with others</td>
</tr>
</tbody>
</table>

**Social Support**

The SSSR had good internal consistency (25 items, $\alpha = .81$). Subscales ranged from poor to excellent, family (5 items, $\alpha = .82$), friends (5 items, $\alpha = .76$), staff (5 items, $\alpha = .41$) and partner (5 items, $\alpha = .95$). Internal consistency for the SCQ was fair (56 items, $\alpha = .77$). The subscales ranged from good to excellent, family (14 items, $\alpha = .93$), staff (14 items, $\alpha = .84$), friends (14 items, $\alpha = .94$) and partner (14 items, $\alpha = .96$). A repeated measures ANOVA with a Greenhouse-Geisser correction indicated that significant differences between subscales existed for the SSSR ($F (2.54, 226.39) = 30.19, p < .01$). Post-hoc analyses with a Bonferroni correction indicated that significantly less support was reported from a partner than the support from other sources. A second repeated measures ANOVA was conducted for the subscales of the SCQ, also with a Greenhouse-Geisser correction ($F (2.48, 161.36) = 37.88, p < .01$). Post-hoc analyses indicated that the amount of support endorsed on the friend and partner subscales were significantly different from one another and from the family and staff subscales. See
Table 4 for comparison of social support subscales means and standard deviations. See Table 5 for reliability between caregiver and self-ratings of social support.

### Table 4. Means and standard deviation by rater and source of support

<table>
<thead>
<tr>
<th>Sources of support</th>
<th>SSSR</th>
<th>SCQ</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
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<tr>
<td>Staff</td>
<td>6.7</td>
<td>2.2</td>
</tr>
<tr>
<td>Friends</td>
<td>5.9</td>
<td>3.0</td>
</tr>
<tr>
<td>Partner</td>
<td>2.9*</td>
<td>3.9</td>
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<tr>
<td>Total</td>
<td>21.6</td>
<td>6.3</td>
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</table>

*Subscale/Scale Range
0-10/0-56

0-44/0-224

*Significantly different from other subscales

### Table 5. Correlation between self and caregiver ratings of support

<table>
<thead>
<tr>
<th></th>
<th>Pearson r</th>
<th>Significance</th>
</tr>
</thead>
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<tr>
<td>Family support</td>
<td>.68</td>
<td>&lt;.001</td>
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<tr>
<td>Staff support</td>
<td>.16</td>
<td>.07</td>
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<td>Friend support</td>
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<td>.04</td>
</tr>
<tr>
<td>Significant other support</td>
<td>.71</td>
<td>&lt;.001</td>
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<tr>
<td>Total support</td>
<td>.18</td>
<td>.04</td>
</tr>
</tbody>
</table>

**Physical Activity**

Internal consistency for the Physical Activity self-report was poor (32 items, $\alpha$=.63) and the caregiver report was good (32 items, $\alpha$=.80). Caregivers reported an average of 3.4 (SD=2.44) activities while self-report yielded an average of 2.2 (SD=1.56) activities. Based on self-report, 42.2% of respondents engaged in adequate amounts of physical activity while according to caregiver rating, 63.3% of respondents engaged in adequate physical activity. Reliability between raters was significant for the number of activities endorsed (ICC=.26, $p<.01$) but not for the composite score that took into
account both number of activities and exertion level (ICC= .06, p=.30). See Table 6 for most frequent activities reported by rater.

<table>
<thead>
<tr>
<th>Table 6. Top 3 activities reported by rater</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-report</strong></td>
</tr>
<tr>
<td>62.2% Walking</td>
</tr>
<tr>
<td>40% Other</td>
</tr>
<tr>
<td>17.8% Lifting weights</td>
</tr>
</tbody>
</table>

_Mental Health:_

Internal consistency for the total PAS-ADD was fair (25 items, α=.76). Subscales were as follows: organic (6 items, α=.68), affective (20 items, α=.74), and psychotic (3 items, α=.65). On the PAS-ADD 23.6% of participants were rated by staff as being above the threshold in one or more of the three subscales that indicates the need for further evaluation. On the organic subscale 8% of participants were above threshold, 14.6% on the affective subscale, and 16.1% on the psychotic subscale. The BSI had excellent internal consistency (53 items, α=.94). Subscale internal consistency ranged from poor to fair: Somatization (7 items, α=.66), Obsessive-Compulsive (6 items, α=.72), Interpersonal Sensitivity (4 items, α=.71), Depression (6 items, α=.70), Anxiety (6 items, α=.74), Hostility (5 items, α=.69), Phobic Anxiety (5 items, α=.65), Paranoid Ideation (5 items, α=.73), Psychoticism (5 items, α=.65). On the BSI, 67.8% of participants met the criteria suggesting the need for further evaluation. On the nine dimensional subscales, 31.1% met cut-off for Somatization, 43.4% for Obsessive-Compulsive, 45.6% for Interpersonal Sensitivity, 43.3% for Depression, 32.3% for Anxiety, 43.3% for Hostility, 44.4% for Phobic Anxiety, 45.6% for Paranoid Ideation, 47.8% for Psychoticism. Only 27.8% of participants were not flagged for further evaluation.
evaluation by either instrument, 48.9% were flagged by the BSI but not the PAS-ADD, 4.4% were flagged by the PAS-ADD but not the BSI and 18.9% were flagged by both instruments. Reliability between raters on total score was significant ($r=.309$, $p<.01$). See Table 7 for correlations between subscales of the PAS-ADD and the BSI. All scores on the BSI are the normed T-scale scores while raw scores were used on the PAS-ADD.
Table 7. Pearson Correlation between PAS-ADD and BSI

|       | PATotal | BSITotal | PAS1    | PAS2    | PAS3    | BSI1    | BSI2    | BSI3    | BSI4    | BSI5    | BSI6    | BSI7    | BSI8    | BSI9    |
|-------|---------|----------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|
| PATotal | 1       | .28**   | .54**   | .88**   | .60**   | .17     | .13     | .17     | .28**   | .25*    | .33**   | .10     | .26*    | .22*    |
| BSITotal | 1       | .27*    | .33**   | .16     | .53**   | .80**   | .81**   | .78**   | .74**   | .80**   | .56**   | .74**   | .78**   |         |
| PAS1   | 1       | .69**   | .50**   | .19     | .22*    | .15     | .19     | .14     | .28**   | .03     | .26*    | .07     |         |         |
| PAS2   | 1       | .59**   | .23*    | .22*    | .20     | .32**   | .23*    | .39**   | .08     | .26*    | .27*    |         |         |         |
| PAS3   | 1       | .06     | .05     | .11     | .09     | .18     | .24*    | .10     | .22*    | .06     |         |         |         |         |
| BSI1   | 1       | .33**   | .30**   | .26*    | .48**   | .36**   | .39**   | .27*    | .37**   |         |         |         |         |         |
| BSI2   | 1       | .63**   | .63**   | .58**   | .64**   | .47**   | .61**   | .62**   |         |         |         |         |         |         |
| BSI3   | 1       | .66**   | .57**   | .66**   | .40**   | .67**   | .64**   |         |         |         |         |         |         |         |
| BSI4   | 1       | .58**   | .61**   | .41**   | .53**   | .66**   |         |         |         |         |         |         |         |         |
| BSI5   | 1       | .57**   | .51**   | .44**   | .50**   |         |         |         |         |         |         |         |         |         |
| BSI6   | 1       | .37**   | .59**   | .62**   |         |         |         |         |         |         |         |         |         |         |
| BSI7   | 1       | .37**   | .46**   |         |         |         |         |         |         |         |         |         |         |         |
| BSI8   | 1       | .61**   |         |         |         |         |         |         |         |         |         |         |         |         |
| BSI9   |         |         |         |         |         |         |         |         |         |         |         |         |         |         |

*P<.05, **P<.01

PATotal=Total PAS=ADD, BSITotal=Total BSI, PAS1=Organic, PAS2=Affective, PAS3=Psychotic, BSI1=Somatization, BSI2=Obsessive-Compulsive, BSI3=Interpersonal Sensitivity, BSI4=Depression, BSI5=Anxiety, BSI6=Hostility, BSI7=Phobic Anxiety, BSI8=Paranoid Ideation, BSI9=Psychoticism
Model of health and health determinants

Prior to testing the theoretical model of well-being, CFA was conducted for both latent variables, mental health and social support, to confirm that use of the subscales of these models were appropriate. The only post-hoc changes made to these models were that highly correlated error terms were allowed to co-vary before assessing final model fit. The social support subscales model was considered to be an acceptable to good fitting model. It should be noted that no subscales were significantly related to one another, when the subscales were treated as exogenous variables to predict a Social Support latent variable the model fit was poor. For this reason, in subsequent SEM models, social support subscales were used instead of a latent social support variable capturing all four subscales. See Table 8 for comparison model fit statistics and Table 9 for subscale model solution.

<table>
<thead>
<tr>
<th>Table 8. Fit Indices for Social Support Models</th>
<th>RMSEA</th>
<th>CFI</th>
<th>$\chi^2$</th>
<th>Relative $\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subscales only</td>
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<td>$\chi^2(161, N=147)=280.97, p=.000$</td>
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<tr>
<td>Subscale loading onto single variable</td>
<td>.22</td>
<td>.36</td>
<td>$\chi^2(167, N=147)=1301.97, p=.000$</td>
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</table>

Two models were tested for the BSI instrument. The first is the 9 factor solution described in the published BSI scoring guide. The second model tested was an 8-factor solution that was suggested following an exploratory factor analysis on a sample of people with borderline and mild ID (Kellett, Beail, Newman, & Hawes, 2004). This 8-factor solution had considerable overlap with the previous 9-factor solution found in the
general population. Both solutions had an acceptable fit based on RMSEA; neither met criteria for a good fitting model based upon CFI. See Table 10 for model fit indices. There was not a clear statistical difference in model fit so a decision was made to use the 9-factor model going forward, see Table 11 for model solution. This decision was based upon greater availability of research on the original 9-factor model, the ability to standardize these scores using the manual, and the increased likelihood that this solution would be widely used by clinicians.
<table>
<thead>
<tr>
<th></th>
<th>Family</th>
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<td>1.10</td>
<td>(.16)</td>
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<td>1.37</td>
<td>(.39)</td>
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**Relationships among factors**

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<th>Friends</th>
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<th>Sig. Other</th>
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</tr>
</tbody>
</table>

\(a=\) Standardized followed by unstandardized loadings with standard errors in parenthesis. One item in each factor is fixed to zero. \(b=\) Bold diagonal contains variance and lower triangle contains correlations, none of which are significant.
Table 10. Fit Indices for BSI Subscales

<table>
<thead>
<tr>
<th>Model</th>
<th>RMSEA</th>
<th>CFI</th>
<th>$\chi^2$</th>
<th>Relative $\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Original 9-factor model</td>
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<td>.67</td>
<td>$\chi^2(1090, N=147)=1967.27$, p=.000</td>
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<tr>
<td>Ketter et al 8 factor model</td>
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<td>.70</td>
<td>$\chi^2(1146, N=147)=1951.53$, p=.000</td>
<td>1.70</td>
</tr>
</tbody>
</table>
Table 11. Standardized solution and unstandardized solutions (standard errors) for 9-factor BSI Subscales

<table>
<thead>
<tr>
<th>Factor</th>
<th>Somatization</th>
<th>Obsessive-Compulsive</th>
<th>Interpersonal Sensitivity</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Hostility</th>
<th>Phobic Anxiety</th>
<th>Paranoid</th>
<th>Psychoticism</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSI2</td>
<td>.34</td>
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**Relationships among factors**

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*a* = Standardized followed by unstandardized loadings with standard errors in parenthesis. One item in each factor is fixed to zero. *b* = Bold diagonal contains variance and lower triangle contains correlations, all of which are significant.
Table 12 shows correlation coefficients between variables in the initial SEM model. There were moderate correlations between the BSI mental health subscales, stress and physical health, stress and mental health subscales, and physical health and mental health subscales. The initial model showed stress having a significant relationship with both physical and mental health. All other pathways were not significant. In order to obtain a more parsimonious and better fitting model, non-significant paths that would not alter the number of variables in the model were deleted. The paths deleted were chosen based on their standardized regression weights (smallest weights were chosen). This resulted in a second model which tested the relationship of stress to both physical and mental health, social support to mental health, and physical activity to physical health, see Figure 2. The resulting model had similar fit indices as the initial model, see Table 13. In the second model, stress was again a significant predictor (p<.001) of mental and physical health. Friends were a significant predictor of the mental health variable (p=.017). In this model 49% (R^2=.49) of the variance in mental health was explained by the social support and stress predictors while only 8% (R^2=.08) of the variance in physical health was explained by the model.
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**=significant at the .01 level, SOM= Somatization, OC= Obsessive-Compulsive, IS=Interpersonal Sensitivity, DEP=Depression, ANX=Anxiety, HOS=Hostility, PHOB=Phobia, PAR= Paranoia, PSY=Psychoticism, SS1=family, SS2=staff, SS3=friends, SS4=partner, PA= Physical Activity, PH= Physical Health
Table 13. Fit Indices for comparison health models

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<td>$\chi^2$=680.454, p=.000</td>
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Figure 2. Secondary Model with Standardized Regression Weights
Chapter 4: Discussion

Scale feasibility for people with ID

One aim of this study was to look at each of the five self-report scales used in this study for their feasibility and validity in a population of people with ID not constrained by a particular level of cognitive functioning. Two of the scales, SSSR and Lifestress Inventory, were designed specifically for people with ID and have been previously researched in this population. One scale, the BSI, was designed for people without cognitive impairment but has seen research in adults with ID. Lastly, two scales the Physical Activity Questionnaire and the Physical Health Questionnaire, were designed by the researcher for this study because scales regarding these constructs could not be found in the ID literature.

Physical Health Questionnaire

The Physical Health Questionnaire, a measure designed for this study, seemed to be easily understood by people with ID. Of the 150 participants, there was only one participant who was unable or unwilling to answer all of the questions. Internal consistency was poor, this is not surprising given the small number of questions on the scale. This scale was developed by the researcher to obtain a brief report of perceived health. While this scale assessed a few common elements of health; health status, sickness that interferes with daily life, and fatigue, there are certainly many other ways to capture physical health that were not included. While this measure appears to have some
face validity, consistency among various raters, and shows an ability to fit with-in a hypothesized model of health, additional research is warranted before treating this as an established and valid method of gathering health related information. Specifically, comparisons with quantitative measures of health such as health records would be helpful in determining validity.

*Lifestress Inventory*

This scale seemed to be easily understood by participants and few concerns or rewording of questions was needed. Internal consistency was poor in this study, slightly worse than was found in previous studies (Bramston, Fogarty & Cummins, 1999; Lunksy & Bramston, 2006). While some concern has been voiced regarding people with ID and the tendency to acquiesce with yes/no questions, a substantial number of the items on this scale are reverse coded to help assess for this possibility (Finlay, & Lyons, 2002). No concerns with acquiescence were noted and participant responses varied as would be expected. Anecdotally, when interviewing participants regarding stress it was noted that a number of participants independently disclosed stress related to major life changes such as moving or changing day program or job placements. Though these types of changes are included on several other scales that capture stressful life events, these things were not captured by the Lifestress Inventory (Holmes & Rahe, 1967; Owens et al., 2004).

**SSSR**

The SSSR was easily understood by participants; of particular help was the initial component which asks a series of guided questions to help identify important people in the person’s life. These guiding questions allow the interviewer to reference specific
people when completing the remainder of the instrument. This was helpful as it was noted that many participants made reference to staff when asked about friendships, this initial “who’s who” allowed researchers to be sure that staff were not inadvertently categorized as friends. The SSSR had good internal consistency as a scale, the sub-scales however ranged from poor (staff) to excellent (partner). This is similar to previous research which also found that self-reported staff support was the most inconsistent (Lunsky & Benson, 1997).

While previous research on this scale has shown that responses on the SSSR are correlated with self-report on a secondary social support instrument and with quality of life, it is unclear how well the total score on the scale related to perceived support (Lunsky & Benson, 1997; 2001). While CFA showed that individual model subscales were a good fit, a model which included an overall social support variable comprised of the four subscales was a poor fit. This was likely due to little to no positive correlations between scales. Given the structure of the scale, this makes conceptual sense. The scale is divided into subscales based on support source and just because an individual has strong supports provided by one source, family for example, does not mean that they have strong supports provided by other sources. In fact, having a strong support from family may mean that the person has less support from staff. For this scale format a person with a strong supportive network that only consisted of one type of support (i.e. family or friends) would have a lower score (theoretically lower social support) than someone with a strong supportive network that consisted of several different types of individuals. Thus this measure places more of an emphasis (in terms of higher scores) on
quantity of support as opposed to quality of support. While research has found that quantity of social support is important, there is also a large pool of research that suggests quality of support, particularly emotional support, may be a stronger predictor of health outcomes (Franks, Cronan, & Oliver, 2004; Glass, & Maddox, 1992).

*Physical Activity Questionnaire*

Internal consistency of this instrument was poor, likely influenced by the small number of endorsed items (average 2.2). However, face validity seemed good with participants able to easily discuss their activities and choose an exertion level. According to this instrument, about half of people in this study engaged in adequate amounts of physical activity. Other studies, using a wide variety of methodologies, have reported that only 18% - 33% of adults with ID engaging in sufficient amount of physical activity (Temple, Frey & Stanish, 2006). Our determination of adequate physical activity was based upon the World Health Organization’s recommendation of a minimum of 150 minutes of moderate intensity or 75 minutes of vigorous intensity physical activity per week (World Health Organization, 2010). In this study, adequate physical activity was defined as engaging in either two activities at moderate intensity or one activity at high intensity per week. Given the results of other studies that have examined physical activity in adults with ID it is likely that this method of collecting data and interpreting adequate amounts of activity resulted in an overestimation. Though participants were given the direction of only endorsing activities that they engaged in regularly, which was defined as at least once per week, it is possible that participants endorsed activities that they engaged in on a less regular basis. The scale did gather a qualitative measure of intensity.
of activity but no measure of duration of activity was collected. Therefore there is no way to know how long endorsed activities last, an essential component in ascertaining whether a person is meeting the minimal requirements for adequate physical activity.

**BSI**

While previous studies on using the BSI as a mental health screener in adults with ID reported positive results and a high degree of understanding by participants, the current study found less favorable results. Weiland, Wardenaar, Fontein, and Zitman (2012), for example, found that an average of 3.9 questions on the BSI were troublesome for participants and required additional explanation, while this study found an average of 7 (SD=6.6) questions to require additional explanation. This means that on average over 10% of the items were not easily understood by participants. Also of note, 15% of participants required clarification of more than 25% (14 questions) of the BSI. In addition, great care was taken to probe for understanding of the BSI questions. When items were endorsed, researchers would often ask participants for an example or ask them to define a word used in the item description. When these probes were used, participants were often unable to voice understanding or give an example, even of endorsed items. While in this study, the researchers took great care to then explain the item differently to the participant and effort was made to ensure understanding, this is above and beyond what is suggested by the BSI manual. The 5-point Likert scale also seemed difficult for many participants, even with the use of visual aids. Lastly, several individual items may have been misinterpreted by adults with ID. For example, “Feeling nervous when left alone” many people voiced that they had 24-hour staff and so were never left alone.
Similarly “Feeling like you are watched or talked about by others” many people referenced staff and caregivers here. Many participants cited their disability when endorsing items on the Psychoticism subscale about cognitive functioning.

Of greater concern than the individual item understanding was the ability of the participants to limit their responses to the given time frame. Though every effort was made by researchers to thoroughly explain the time frame and give temporal markers, most participants had trouble staying within this frame. This was evident by participants endorsing items and giving examples or stories related to the item that were clearly in the past, at times years previous. Since most mental health concerns necessitate a change from baseline functioning within a given time frame, great care is needed to establish the time of an event or change for adults with ID. These clinical concerns were mirrored by statistical concerns that arose during the CFA of the subscales of the BSI. Two models, the original model from the BSI manual and the model proposed by Kellett et al. were tested and neither model proved to be a good fit to the data (2004).

Despite the above concerns, the BSI did appear to be measuring variance related to mental health concerns. The study also found the results of the BSI to be significantly correlated with stress and found significant correlations with staff report, further indicating that the BSI was able to capture information regarding mental health symptoms. However, the previously stated concerns raise significant question about whether the BSI is, in fact, a robust and valid instrument for the wider ID population. Given the many concerns with the subscales, and the high rate of participants meeting cut-off it may be that the scale does not perform well as a screening instrument for this
population and that the subscales may not provide helpful or valid information. One reason that this study found less favorable results than previous work may have to do with the functioning level of participants. In previous studies examining the use of the BSI for people with ID, the majority of the participants were described as having borderline or mild ID. In this study no constraints were placed on IQ level and a significant portion of the sample had a diagnosis of moderate ID. The high rates of mental health concerns combined with the difficulties associated with diagnosis and treatment in people with ID make the development of a scale to collect information on mental health symptoms directly from people with ID is essential (Einfeld, Tonge, Chapman, Mohr, Taffe & Horstead, 2006; Reiss, & Szyszko, 1983; Scott & Havercamp, 2015).

Reliability between self and proxy report

The final aim of this study was to examine agreement between people with ID and their caregivers on various health related factors. Self and caregiver report were compared for 5 different areas of life: mental health, social support, stress, physical activity, and physical health. Stress, physical activity, and physical health were all measured using the same instrument, with minor wording changes, for both groups while mental health and social support were measured using different instruments. All self-report scales were conducted in an interview format while all caregiver reports were completed independently. Concordance between staff and self-report varied widely between scales and within individual scales

Physical Health:
Agreement between caregivers and participants was fair for the physical health questionnaire. In general, people with ID were more likely to rate their health as very good whereas proxy reporter were more likely to give a fair/poor rating. Few other studies have used self-report to gather information regarding physical health status in adults with ID; however, research from other areas suggests that proxy reporters may overemphasize the person’s perceived impairments when rating aspects such as stress and health related quality of life (Andresen, Vahle, & Lollar, 2001; Bramston, Fogarty, & Cummins, 1999). A similar pattern may be emerging here with proxy reporters tending to focus more on the person’s disability when rating health.

**Stress:**

Concordance between caregivers and self-report was poor for the Lifestress Inventory. Similar to previous studies, people with ID tended to report more stress than their caregivers (Bramston, Fogarty & Cummins, 1999; Lunksy & Bramston, 2006). When staff reporters and family reporters were considered separately, a different picture emerges. The stress reported by family members correlated moderately well with self-reported stress but the agreement between staff and self-report was non-significant and poor. Participants for whom family members completed the survey were likely to be living with their family, perhaps giving family members better insight into both the day to day stressors (hearing people arguing) and the major life stressors (death or illness of a person close to them) impacting the adults with ID. Previous research that reported higher concordance between staff and self-report was based on a sample that included a high proportion of staff who were also family members (Lunksy & Bramston, 2006). In that
better agreement was reported between family members and self-report than between staff and self-report. It is also noteworthy that there is no time frame given on the Lifestress Inventory. Poor agreement between staff and self-report may be partially a reflection of participants with ID endorsing stressors that may have occurred in the past that were unknown to the staff member. In this sample, there was a substantial number of staff (35%) who had known the participant for one year or less. Despite the relatively low correlations between informant reports and self-reports of stress, three of the top five stressors reported by participants and proxies were the same.

**Social Support:**

Concordance between raters on quality and quantity of social support varied from poor to substantial by support source being rated. The agreement between proxies and self-report was closer when rating family and significant other support than for staff and friends. The high concordance between raters on the significant other variable was influenced by the fact that many participants did not have a significant other so there were many “no support” ratings for that section. Proxy report and self-report agreed that participants received the most support from staff, followed by family, friends, and significant others. A study by Lunsky & Benson (1997) which compared staff, using the SCQ, and self-report, using the SSSR, found similar results, though in that sample, staff rated support from family as significantly lower than support from staff and friends. While a paid caregiver or family member may be able to accurately rate their own relationship with an individual, they are unlikely to be privy to other relationships that may occur in a different setting. For example, a residential caregiver may not be aware
of the relationships that the participant has with staff at a day program or work site. Similarly, caregivers may be unaware of friendships that may exist in different settings. Anecdotally, many staff members verbalized feeling unequipped to rate the relationships of the person with ID, often stating that they were unaware of friendships/intimate relationships or had never seen the person interact with a friend/significant other.

**Physical Activity:**

Agreement between raters was fair to poor for the Physical Activity Questionnaire, though there was higher agreement for number of activities alone than when both number and intensity of activities was considered. This suggests caregivers are more likely to agree with participants about what activities are completed but may have different opinions about the intensity of those activities. Though identical instructions were provided to both caregivers and participants with ID regarding what constituted regular engagement in activity (a minimum of 1-2 times per week), it is possible that participants differed in their interpretation of “regularly.”

**Mental Health:**

The PAS-ADD identified 23.6% of participants as scoring in the at-risk category of mental health symptoms, which is similar to results from other studies, while self-rating of symptoms on the BSI resulted in 67.8% of participants scoring above cut-off (Allen, Lowe, Matthews, & Anness, 2012; Taylor, Hatton, Dixon, & Douglas, 2004). A moderate correlation was seen between self and proxy report on symptoms of mental health as rated by the BSI and the PAS-ADD. People with ID were much more likely to score above the cut-off for requiring further evaluation using the BSI to self-report.
symptoms than caregiver’s reports using the PAS-ADD. Similar to the total score, many more participants met the cut-off scores for BSI subscales than for PAS-ADD subscales. While these results might be an actual reflection of adults with ID experiencing much more symptomology than caregivers perceive, it is also important to consider these results with-in the context of the difficulty outlined previously in using the BSI in the current sample. Given that some people with ID are unable to communicate and proxy report of mental health symptoms is the only avenue for diagnosis and treatment it is an important direction for future research to continue to investigate the relationship and possible discrepancies between proxies and self-report.

*Model of health and health determinants*

Results from this study indicate that self-report data from adults with ID can be used to provide useful information regarding health and health determinates. Though previous research has explored self-report on factors of health, this is the first time that data has been integrated into an exploratory model. Three factors, social support, stress, and physical activity were all hypothesized to impact both mental and physical health based upon previous research. While the first model which tested direct paths from each determinant to both physical and mental health was judged to have an adequate fit, a second model with fewer paths was tested based upon several low factor loadings, specifically social support’s impact on physical health and the impact of physical activities on mental health. This second model, while not statistically different from the first model, was more parsimonious and had slightly better fit indices, thus was considered the better fitting model.
While it was hypothesized that all three factors would have an impact on physical and mental health, stress was the only factor found to be significantly associated with physical health. Increased stress was associated with increased risk of being in poorer self-reported health. This is in line with a plethora of research that has shown high level of stress to negatively impact physical health (Dimsdale, 2008; Öhlin, Nilsson, Nilsson, \& Berglund, 2004; Segerstrom, \& Miller, 2004). Stress was also a significant predictor of mental health with higher perceived stress corresponding to higher levels of symptomology. This also is in line with previous research in both people without disabilities and people with ID (Marin et al., 2011; Owen et al., 2004; Scott \& Havercamp, 2014). These results add to the evidence showing that for people with ID, stress is an important factor to understanding health. These results also show that adults with ID are able to accurately report on stressors that may impact important outcomes, particularly health outcomes.

Stress should be considered a risk factor for poor health outcomes. This is particularly important given the research that shows people with ID experience unique stressors and have less support available to cope with these stressors (Hastings, Haton, Taylor, \& Maddison, 2004; Lunsky \& Benson, 2001). Recognizing the impact of stress, taking steps to improve interpersonal stresses, which people with ID often report, and providing additional support in times of unavoidable stress may all be tangible ways in which to indirectly improve health outcomes.

An unexpected result was the significant predictive power of friendship on mental health symptoms. This effect was in the opposite direction as would be expected with
higher levels of friendship associated with higher levels of mental health symptomology. This was a surprising finding and though no definitive explanation can be given, a few hypotheses are put forth. Certainty it is possible that this is a spurious finding but given the lack of research investigating the impact of social support as reported by people with it is important to consider alternate explanations. In the Lifestress Inventory, one of the most frequently reported stressors was being exposed to interpersonal stressors like hearing people arguing. Anecdotally, many people expanded on the endorsement of that item by talking about disagreements between roommates or other people at their day program or worksite. It may be that some of the friendships reported are volatile and may add stress to the person’s life. It is also possible that some of the friendships reported were not high quality supportive friendships but rather a desire for friendships. There has been some research that suggests many people with ID have infrequent contact with people they name as friends or contact that is based on proximity rather than based on shared interest or mutual support (Bigby, 2008; Cummins & Lau, 2003). To further explore this possibility, the individual friendship items were further examined. The vast majority of participants, 90%, reported that they liked their friends a lot and most, 81%, said that if their friend had a problem they would sometimes or always help them. In contrast, 35% of people said they would never talk to their friends about their feelings/emotions and only 40% of people felt their friends would always help them if they had a problem. Even though the majority of the participants reported having friends, only 60% said that they saw or spoke to their friends a lot. This pattern may indicate that while people clearly desire friendship, as evidence by reporting friendships, liking their
friends, and being willing to help them, at least some of these friendships may not be providing people with the emotional support that might positively impact outcomes. In fact, a strong desire for friendship that in unrequited may negatively impact mental health. Given the lack of research on using the SSSR as a measure relating to outcomes, and the lack of clarity regarding how friendships may be impacting people with ID additional research is certainly need to fully understand how social support may impact the health of people with ID.

Physical activity was not a significant predictor to either of the health indicators. While research in people without disabilities has drawn a positive link between physical activity and health outcomes the research on people with ID is still emerging. One reason may be the difficulties measuring physical activity in his population and understanding the various complexities underlying the mechanisms through which people with ID are able to access physical activity (Peterson, Lowe, Peterson, Nothwehr, Janz, & Lobas, 2008). As this model used a novel scale for assessing amount of physical activity, it is hard to assess whether the nonsignificant results are a true representation of the impact of exercise for this population or reflective of a measurement problem. More research is needed on how to best measure relevant aspects of physical activity and the impact of physical activity on health outcomes.

*Clinical considerations for using proxy report*

This study found that agreement between self and proxy report varied by instrument, from poor to moderate. These findings add to the growing literature establishing the importance of considering the self-report of adults with ID. This appears
to be particularly relevant for questions or concepts that require reporting on internal thoughts or feelings, such as social support, stress, and mental health symptoms. Given the results of this study and previous research (Lunksy & Benson, 1997), it is likely that caregiver report of social support is largely unreliable for rating support from friends and staff people. Though previous studies on stress have reported higher rates of agreement, this study found that proxy and self-report were not significantly related. Though this was the first study to compare self and proxy report on mental health symptoms, vast differences between reporters indicate that this may be another area for which proxy reporting is inadequate.

While there are some people with ID who are unable to self-report in any capacity, the results of this study and other recent studies (Stancliffe, Tichá, Larson, Hewitt, & Nord, 2015) demonstrate that it is possible to obtain information directly from many adults with ID on a variety of topics. Given the results of this study, it is recommended that concentrated effort should be made in both research and practice to obtain self-report from any person with some capacity for communication. When proxy reports must be used, they should be used with caution, particularly when dealing with subjective subject matter. Proxy reports from staff members may be particularly concerning as staff often have known a person for a limited amount of time and may only see that person in one context. When self-report is not feasible, it is recommended to gather proxy report from more than one source if possible, especially if the only sources available are staff. Clinicians should make a concentrated effort to seek out and utilize
scales that have been developed and tested for people with ID when using either self or proxy report.

*Future Directions*

The majority of the scales used in this study seemed to perform well in a sample of adults with ID, however, they all could benefit from additional research. The physical health and physical activity scale used in this study were created by the researcher for this study. Although they were designed with consideration given to Finley and Lyons (2001) recommendations and seem to have utility, addition research is needed. Future studies should more rigorously test validity and reliability, specifically by comparing results to objective measure of health and physical activity.

Both the Lifestress Inventory and the SSSR have been used successfully in the past to gather self-report from adults with ID. Similar to previous studies, these scales were easily understood and provided valuable information. Future research on the Lifestress Inventory may consider adding in items to capture stress related to changes in life circumstance such as changing jobs or living situations and impose a time constraint to better capture recent events. For the SSSR, future research may consider an alternative scoring rubric and/or additional items to ensure that the scale is adequately capturing quality of support, particularly in terms of friendships.

Though previous research, which included only people with borderline or mild ID, reported good psychometric properties and comprehension when using the BSI as a screener for mental health symptoms, when used in a sample with a wider range of cognitive skills, results were less positive. Based on the concerns with comprehension,
time orientation, and subscales, the use of the BSI may be restricted to adults with mild or borderline ID. There have been many scales developed for people with ID by modifying existing instruments that have been developed for people without disabilities (Bramston, Bostock, & Tehan, 1993; Lunksy & Benson, 1997). This may be a possibility with the BSI. Several areas that should be addressed are simplifying the wording when possible, changing items with abstract concepts, simplifying/clarifying the response scale, and validating and norming both the subscales and the instrument as a whole for people with ID. These changes would likely greatly improve the utility of this scale, though difficulties regarding temporal anchoring are still a concern. Modifying an existing instrument like the BSI or developing an appropriate self-report instrument for assessing mental health symptoms of adults with ID is of the upmost importance given the prevalence of mental health concerns in people with ID. Since many common mental health symptoms are intrinsically linked to subjective reports (feeling sad, guilty, worried) having an instrument with strong psychometric properties for use in this population would have great clinical and research utility.

Limitations

One limitation of this study is the small sample size (Bentler, & Chou, 1987; Tanaka, 1987; Wolf, Harrington, Clark, & Miller, 2013). Though this sample size was adequate for the tested model, the sample size limited the ability to test a confirmatory model or to run more complex analyses. Therefore it is recommended that the SEM models and analyses be treated as exploratory and that future research replicate these finding with a larger sample.
A second limitation of this study is the use of several novel instruments and the novel use of several established instruments. Two instruments, Physical Activity Questionnaire and Physical Health Questionnaire were created for the purpose of this study. Though anecdotally they appeared helpful in gathering information in this population, further research is needed to test validity and reliability. Though the BSI has been recommend for use in adults with ID, the current study encountered comprehension concerns in this sample. Further research is needed on this instrument in people with ID.

Lastly, this study relies entirely upon subjective report from participants at a single time point. There was no way to compare responses to quantitative evidence such as current diagnosis, to confirm report of activities participated in or to validate reciprocity in friendships endorsed. Additionally, the relationship of variables to one another were explored at a single time point while the relationship of social support, physical activity, and stress to health is a complicated one with fluctuations and bi-directional relationships that could be better explored by a design that was able to capture change over time.
Conclusions

Despite these limitations, the results of this study contribute to the literature on health in people with ID in three important ways. First, it provides additional information on several established scales and initial results on the use of two new scales for gathering health related information in a diverse group of adults with ID. While some scales performed well in this study, particular concern was raised regarding the use of the BSI as a screener for mental health concerns. Second, this study showed that self-report can be used to gather information on a variety of health related factors without use strict inclusion criteria based upon cognitive functioning. Lastly, though exploratory in nature, this study uses self-report data to conceptualize and test a model of health in people with ID. The model showed stress, as reported by participants, to be a powerful predictor of health outcomes, confirming that self-report can provide valuable and informative data on the lives of people with ID.
References


Lunsky, Y., & Benson B. A. (2001). Association between perceived social support and strain, and positive and negative outcomes for adults with mild intellectual disability. Journal of


Appendix A. Recruitment Flyer
Want to participate in Research?

**Purpose**

Researchers at the Ohio State University are interested in what factors influence the well-being of adults with Intellectual Disability.

**Who can participate?**

Adults with a diagnosis of Intellectual Disability who are able to respond to questions, either verbal or written, and have a caregiver who is willing to participate.

**What will I do?**

A researcher will meet with you at the place of your choosing and ask you questions about your health, the people in your life, stress that you experience, and your exercise habits. You will also be asked to identify a caregiver that can answer these questions about you. The study will take approximately 1.5 hours to complete. You will receive a $15 gift card for your participation.

**Contact**

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330-317-9274
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Appendix B. Demographic Forms

Participant Demographic Information: Self-Report

Participant ID: _____________
Date: ________________

Directions: Please provide the following information about yourself using the blank spaces provided or check the answer that best fits you.

1. Age (in years): _______________

2. Gender:  
   □ Female (1)  
   □ Male (2)

3. Ethnicity (please check all that apply):
   □ Prefer not to respond (0)  
   □ Asian/Pacific Islander (4)  
   □ Black or African American (1)  
   □ Native American (5)  
   □ Caucasian/White (2)  
   □ Bi-racial/Multi-racial (6)  
   □ Latino/Latina (3)  
   □ Other (please describe) (7) _____________

4. Marital Status:  
   □ Single (1)  
   □ In a romantic relationship, but not married (2)  
   □ Married (3)  
   □ Divorced/Separated (4)  
   □ Other (please describe) (5) _______________

5. Current Living Situation:
   □ Independently - Alone (1)  
   □ Supported Living (5)  
   □ Independently - Roommate(s) (2)  
   □ With romantic partner (6)  
   □ Less than 24 hrs support staff - Alone (3)  
   □ With family (7)  
   □ Less than 24 hrs support staff – Roommate(s) (4)  
   □ Other (please describe) (8):_______

6. Are you employed?  
   □ Yes - Full-time (40 or more hours/week) (1)  
   □ Yes - Part-time (less than 40 hours/week) (2)  
   □ No – Have had a job in the past (3)  
   □ No – Have never been employed (4)

7. If you are currently employed, what is your occupation/job?

   ________________________________

8. If you are not currently employed but have been in the past, what is the job that you have held for the longest period of time?

   Job: ____________________________  
   How long? ____________________
Participant Demographic Information: Caregiver Report

Participant ID: __________

Date: _________________

Directions: Please provide the following information about client/family member who is participating in the study.

1. Participant age (in years): ______________

2. Gender:
   - □ Female (1)
   - □ Male (2)

3. Ethnicity (please check all that apply):
   - □ Prefer not to respond (0)
   - □ Asian/Pacific Islander (4)
   - □ Black or African American (1)
   - □ Native American (5)
   - □ Caucasian/White (2)
   - □ Bi-racial/Multi-racial (6)
   - □ Latino/Latina (3)
   - □ Other (please describe) (7)

4. Marital Status:
   - □ Single (1)
   - □ In a romantic relationship, but not married (2)
   - □ Married (3)
   - □ Divorced/Separated (4)
   - □ Other (please describe): __________________________ (5)

5. Current Living Situation:
   - □ Independently - Alone (1)
   - □ Supported Living (5)
   - □ Independently - Roommate(s) (2)
   - □ With romantic partner (6)
   - □ Less than 24 hrs support staff - Alone (3)
   - □ With family (7)
   - □ Less than 24 hrs support staff – Roommate(s) (4)
   - □ Other (please describe) (8): _______

6. Does your client/family member have a job?
   - □ Yes: Full-time (40 hours/week) (1)
   - □ No – Have had a job in the past (3)
   - □ Yes - Part-time (less than 40 hours/week) (2)
   - □ No – Have never been employed (4)

7. If he or she is currently employed, what is her occupation/job?
   a. ________________________________

86
Parent-Caregiver Demographic Questionnaire

Participant ID:__________
Date: _________________

Please provide the following information using the blank spaces provided or check the answer that best fits you and your family.

1. Age (in years):_____________________

2. Gender:
   □ Female (1)
   □ Male (2)

3. Ethnicity (please check all that apply):
   □ Prefer not to respond (0)
   □ Asian/Pacific Islander (4)
   □ Black or African American (1)
   □ Native American (5)
   □ Caucasian/White (2)
   □ Bi-racial/Multi-racial (6)
   □ Latino/Latina (3)
   □ Other (please describe) (7) ______________

4. Your relationship to participant (check all that apply):
   □ Mother (1)
   □ Other family member (6)
   □ Father (2)
   □ Paid caregiver-residential (7)
   □ Grandmother (3)
   □ Paid caregiver-day program (8)
   □ Grandfather (4)
   □ Paid caregiver-other (9)
   □ Legal Guardian (5)
   □ Other (please describe) (10) ______________

5. If you are a legal guardian, adoptive parent, or other family member, how old was your son/daughter/family member when you began caring for him or her (in years)?
   ________________________________________________________________________________

6. If you are a paid caregiver how long have you been working with him or her (in years)?
   ________________________________________________________________________________

7. What is the highest degree you have earned:
   □ High School Diploma (1)
   □ Master’s Degree (4)
   □ Associate’s Degree (2)
   □ Doctoral Degree (5)
   □ Bachelor’s Degree (3)
   □ Professional Degree (6)
   □ Other (please describe): (7) __________

8. Are you employed?
   □ Yes - Full-time (40 hours/week) (1)
   □ Yes - Part-time (lessthan 40 hours/week) (2)
   □ No (3)

9. If you are currently employed, what is your occupation/job? ____________________________
Appendix C. BSI Standardized Alternate Wordings

1. Feeling nervous or shaking (mime action)
2. Feel faint or get dizzy
3. Do you feel like someone else can control your thoughts or is making you do things
4. Do you feel like it is other people’s fault when things go wrong in your life
5. Forget things a lot
6. Get angry at people easily
7. Chest hurts (point to area)
8. Feel afraid when out in the community (give example)
9. Think about killing yourself or wanting to die
10. Feeling that people around you can’t be trusted
11. Not wanting to eat/changes in eating
12. Feel scared for no reason
13. Get angry/yell and can’t control it
14. Feel lonely even when there are people with you
15. Can’t get things done when you need to (give example)
16. Feel lonely
17. Feel sad
18. Don’t want to do things you usually like
19. Feeling afraid
20. Get upset easily
21. Do people like you (reverse code)
22. Feel like you are not as good as other people
23. Stomach hurts/feel sick
24. Feel like someone is watching you or talking about you
25. Do you sleep well (reverse coded)
26. Do you have to check you work/chores over and over
27. Have trouble deciding things (give example)
28. Feel scared to travel (give example)
29. Trouble breathing (mime)
30. Get too hot or too cold when the temperate is okay/not changing
31. Are there places/things/activities that you can’t do because you get too scared
32. Can’t think/Mind is empty
33. Parts of your body (give example) feel numb or tingly
34. Feel like you should be punished for bad things you have done
35. Do you feel excited about the future (reverse code)
36. Mind wanders when you try to complete a task
37. Parts of your body feel weak/don’t work
38. Body feels tight/tense (mime)
39. Think about death or dying
40. Do you think about hurting people
41. Do you think about breaking things
42. Do you feel embarrassed around people/think they are judging you
43. Do you feel uncomfortable in crowded places (give example)
44. Feel like you don’t have a close friend/someone to talk to
45. Get suddenly scared or panic for no reason
46. Get into fights/arguments with people a lot
47. Feel scared if you are alone
48. When you do a good job do people notice (reverse coded)
49. Have trouble sitting still (mime)
50. Do you feel like you are not important
51. Will people take advantage of you if you let them
52. Do you feel bad about things you have done
53. Do you feel like something is wrong with your brain or it doesn’t work right

Visual Aid Material:

0=Not at all  1= A little  2=Moderately  3=Quite a bit  4=Extremely
Appendix D. Physical Health Questionnaires

Participant ID_____
Date_____

Physical Health Questionnaire

Do you feel too tired to do the things you want to do? (this got reverse coded)

1. Yes, most of the time
2. Sometimes
3. No or rarely
4. Don’t know

Do you think your health is

1. Very good
2. Fair
3. Poor
4. Don’t know

Do you feel too sick to do the things you want to do? (this got reverse coded)

1. Yes, most of the time
2. Sometimes
3. No or rarely
4. Don’t know
Physical Health Questionnaire-Caregiver Version

Does she/he feel too tired to do the things he/she wants to do?

1. Yes, most of the time
2. Sometimes
3. No or rarely
4. Don’t know

How would you rate his/her health?

1. Very good
2. Fair
3. Poor
4. Don’t know

Does he/she feel too sick to do the things he/she wants to do?

1. Yes, most of the time
2. Sometimes
3. No or rarely
4. Don’t know
Appendix E. Physical Activity Questionnaires

Participant ID_______
Date_______

Physical Activity Questionnaire

Which of the following activities do you do regularly (At least 1-2 times per week)? Think about all aspects of your life including Special Olympics, outing with your day program, work, or belonging to a gym. Please circle each activity that applies and then rate the intensity of the activity.

1. Swimming
   When you do this activity are you out of breath/sweating/tired? 0 1 2

2. Walking for exercise
   When you do this activity are you out of breath/sweating/tired? 0 1 2

3. Basketball
   When you do this activity are you out of breath/sweating/tired? 0 1 2

4. Baseball/Softball
   When you do this activity are you out of breath/sweating/tired? 0 1 2

5. Running/Jogging
   When you do this activity are you out of breath/sweating/tired? 0 1 2

6. Lifting weights
   When you do this activity are you out of breath/sweating/tired? 0 1 2

7. Riding a bike
   When you do this activity are you out of breath/sweating/tired? 0 1 2

8. Skating
   When you do this activity are you out of breath/sweating/tired? 0 1 2

9. Football
   When you do this activity are you out of breath/sweating/tired? 0 1 2
10. Soccer

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

11. Volleyball

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

12. Tennis

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

13. Snowboarding/skiing

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

14. Using exercise equipment at a gym

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

15. Dancing/using an exercise video

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

16. Other ______________

| When you do this activity are you out of breath/sweating/tired? | 0 | 1 | 2 |

Visual aid material:
Physical Activity Questionnaire-Caregiver

Which of the following activities does he/she do regularly (At least 1-2 times per week)? Think about all aspects of his/her life including Special Olympics, day program outing, work, or belonging to a gym. Please circle each activity that applies and then rate the intensity of the activity.

1. Swimming
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

2. Walking for exercise
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

3. Basketball
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

4. Baseball/Softball
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

5. Running/Jogging
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

6. Lifting weights
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

7. Riding a bike
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

8. Skating
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

9. Football
   When he/she does this activity are they out of breath/sweating/tired? 0 1 2

10. Soccer
When he/she does this activity are they out of breath/sweating/tired? 0 1 2

11. Volleyball

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

12. Tennis

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

13. Snowboarding/skiing

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

14. Using exercise equipment at a gym

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

15. Dancing/using an exercise video

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

16. Other____________________

When he/she does this activity are they out of breath/sweating/tired? 0 1 2

Please use this space to make any additional comments that you think the researcher may find helpful:

____________________________________________________________________________
____________________________________________________________________________